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**‘Made with love, filled with hope’. Knitted Knockers and the materiality of care:
their impact on the women who make and receive them.**

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Abstract

This reflective case study sets out to ask ‘How do participatory textile-making projects engage and impact participants and recipients?’ by focussing on Knitted Knockers UK, a global network of knitters who voluntarily create prosthetics for women following mastectomy or lumpectomy. The article examines the choices women are faced with following breast cancer surgery, and considers ‘softer options’ to surgical reconstruction, including knitted prosthetics. Drawing on qualitative data gathered via personal communications and social media, personal experience of breast cancer diagnosis and treatment, and feminist discourse with relation to breast cancer and the body, the authors evaluate the relationship between well-being, healthcare and digitally connected knitting communities. They offer reflections on the materiality of care the Knitted Knockers represent and consider the role these hand-knitted prosthetics can play in providing a sense of community and emotional well-being for both the creators and the recipients of these knitted gifts.

Keywords: community, craft, healthcare, well-being, knitting, socio-material engagement

Introduction

This reflective case study sets out to ask ‘How do participatory textile-making projects engage and impact participants and recipients?’ Knitted Knockers UK is a network of knitters who voluntarily create prosthetics to be sent as a gift, to be worn by women who have opted not to have reconstruction, either immediately after breast surgery, or as a long-term permanent choice. The article will examine the choices women are faced with following breast cancer surgery, and considers ‘softer options’ to surgical reconstruction, including prosthetics such as Knitted Knockers. It will offer some reflections on the materiality of care

the Knitted Knockers represent and will consider the role these prosthetics can play in providing a sense of community and emotional well-being for both the creators and the recipients of these hand-made gifts.

Methodological Approaches

The article draws on qualitative data gathered via personal communications and data from social media and auto-ethnographic reflections arising from one of the author's direct experience of breast cancer diagnosis and treatment, in order to evaluate the relationship between well-being, healthcare and digitally connected knitting communities. The empowerment experienced by users of the knitted knockers is also examined. The study is conceptually underpinned by research into the history of breast cancer treatment and current medical approaches to reconstruction, as well as feminist discourse of the body with relation to breast cancer, and cultural norms of 'wholeness'.

The Research Context: Breast Cancer and Breast Reconstruction

Breast cancer is the most common cancer in women worldwide. In the UK alone, one in seven women will develop it in their lifetime (World Health Organization, 2019; Cancer Research UK, 2019). The majority of women diagnosed will undergo surgery to remove the primary tumour, and may go on to have chemo and radiotherapy post-operatively. A number of these women will require a lumpectomy or mastectomy, and be offered 'breast restoration' or 're(making) of the normal' (Sandell, 2008, p.326) in the form of a removeable prosthesis or reconstruction surgery.

Not all women opt for breast restoration, and increasingly women are questioning the societal norms with respect to women's bodies and notions of beauty and wholeness.¹ This is one reason why breast cancer has been a subject of feminist activism since the 1970s, through the writings of those with direct experience of the illness such as Dorothy Broom, Nancy Datan, Audre Lorde, Deena Metzger, and Susan Sontag.² Feminist approaches to the illness are seen as an antidote to what Wilkinson describes as the coercive 'discourses and practices' of concealment, blame and responsibility which beset women with breast cancer, often promulgated by the medical profession (Wilkinson, 2001). Broom, cited in Wilkinson, writes that following a diagnosis, women with breast cancer are 'generally expected to resume their usual obligations with no visible mark of their loss, no allowance for their grief, and no concession to the fact that the world has been irrevocably changed'

(Wilkinson, 2001, p. 270). The expectation of concealment also manifests itself in the options presented to women post-surgery:

At the centre of this concealment is the absolutely routine assumption that after breast surgery, a woman will be fitted for a prothesis (or undergo breast reconstruction) – so that her outward appearance to the world is unchanged and ‘no one will know’ she has had breast cancer. (Wilkinson, 2001, pp. 271-2)

The decision to undergo breast reconstruction is clearly very personal, however it can be argued that the pressure to conform to cultural norms of ‘wholeness’ may force women into surgical reconstruction. Today, breast reconstruction is increasingly recommended immediately post-mastectomy, with the benefit of only requiring one operation being cited (Rolph, Mehta and Farhadi, 2016, p. 334). Another benefit for immediate reconstruction is cited as ‘minimal loss of body image for the patient’ (Rolph, Mehta and Farhadi, 2016, p. 334.). The suggestion is that the unfortunate experience of mastectomy can be minimized or even normalized through reconstruction. As Sandell writes:

The general understanding, put forward within medical practice, in medical and psychological research, as well as by patients, is that women feel mutilated after mastectomy. Losing a breast is also losing a part of one’s femininity, and reconstruction can help restore the body image and a sense of attractiveness, and even help one getting over cancer. (Sandell, 2008, p.326)

Reconstructive surgery is not without risks, and whether a woman opts for prosthetic or autologous (using patient derived tissue) reconstruction, it can lead to significant clinical complications.³ The psychological impact of a breast cancer, from detection, diagnosis and treatment, is also significant, making the decision whether to have surgical reconstruction highly stressful. Fasse et. al. cite that treatment options, including reconstruction, ‘are mostly left to surgeons’ (Fasse, Flahaut, Vioulac, et al., 2017, p. 255). Thorne and Murray (2000) contend that complex social constructions and norms also impact the ways in which women experience breast cancer, and can influence their decisions when facing treatment options. This discourse, they argue, is largely missing in professional and health sciences analysis (Thorne and Murray, 2000, p.142).

Although surgical reconstruction following lumpectomy or mastectomy is the anticipated route as a part of ‘recovery’, women who wish or need to delay their reconstruction are provided with a prosthetic, as is the case for the minority of women who decide not to have a reconstruction. Breast protheses offer a less invasive post-mastectomy choice for women. They are largely made of silicone gel encased in film, come in a variety of different shapes, weights and skin tones, and are designed to fit in a bra

(<https://www.breastcancercare.org.uk>). Prosthesis manufacturers capitalize on connecting the ideal breast form with images of gendered feminine beauty, with manufacturers claiming to be 'helping women feel beautiful again' (Gardner, 2000, pp. 584). It is clear that advancements in the prosthetics industry, for many women, have provided a positive and restorative outcome to a traumatic and life altering process. But it is also apparent that this is a burgeoning industry. To what extent has this industry colluded with reinforcing a feminine ideal, one that tells post-mastectomy women they are no longer 'whole'?

The Making Activities: Exploring Softer Options

Silicon breast prostheses have a number of significant drawbacks including their weight and the synthetic nature of the material. Many women describe difficulties of using the prosthesis as the equivalent of carrying a heavy handbag on their shoulder. The 'technical' qualities of these silicone breasts seem almost oxymoronic when placed against the female body for which they are designed. Cromptvoets writes:

As a 'bit of plastic', these devices cause rashes and discomfort, require cleaning, and demand constant surveillance to ensure they do not reveal themselves or the truth about the woman's maimed body. (Cromptvoets, 2012, p.118)

Canadian feminist, educator and knitter, Beryl Tsang found the silicone prostheses on offer following her mastectomy to be 'hot, ugly, heavy and expensive', requiring 'specialist bras that were unattractive' (Petney, 2008). In response, she created her own range of knitted breasts in a variety of colours, textures and sizes, using soft luxury fibres such as cashmere and mohair, with patterns freely downloadable on her website 'Titbits'

(http://www.titbits.ca/v1/tb_home.html). Petney writes:

By rejecting mainstream options for mastectomy patients – that is, breast augmentation surgery or expensive prostheses – Tsang subverted the available subject position for women with breast cancer (as patient, victim, and consumer of medical products) [...] Creating a personalized breast out of yarn, however small a gesture it may seem, shifts the emphasis from dependency on the medical system to women's self-healing, creativity and humour. (Petney, 2008)

Increasingly, women like Tsang are questioning the options offered by the medical profession and seeking alternative solutions. Thanks largely to social media women are becoming aware of alternatives to the mainstream provision of such prostheses. From a feminist perspective, this mirrors the rise of online activist knitting groups that have provided

an important outlet for personal expression and an opportunity to reclaim craft from its associations with feminine subjugation (Robertson, 2011).

For women in Britain, Knitted Knockers UK (KKUK) founded by Jo Dervisoglu, offers free-of-charge hand-knitted or crocheted 'Knockers' using lightweight cotton, which is soft against the skin and breathable. Women who would like to use a Knitted Knocker or would like a Knitted Knocker to be sent to someone, contact KKUK via their website page and complete a form to make their request. There are 114 Knitted Knocker groups in the UK and in the first six months of 2019, 2608 Knockers were created and sent out to women across the country (<https://www.kkukciowix.com>).

There are currently 600 volunteers within the KKUK community, most are knitters but a few members are supporters and/or fundraisers. Anyone wishing to become a knockerette (the name given to a member) has to be an experienced knitter, able to use double pointed needles or circular needles, and is required to go through an application process which includes knitting a sample prosthesis from a pattern which is specific to the group and not available elsewhere. This robust application process is to ensure a high and equitable standard of knitting across the group. Once an application is accepted, a volunteer is then able to join a closed Facebook group – Knitted Knockers UK Community Board. Most of the charity's business is done electronically via this channel as there are knockerettes across the British Isles. Orders are allocated and approved online and supplies of approved yarn are distributed by post along with the packaging materials.

Despite the geographical spread of the volunteers, the bond between the women in this community is very strong. Volunteers use the closed Facebook group to provide advice and support for each other about knitting and other aspects of the charity, as well as aspects of their own life. If a volunteer is going through a difficult time, fellow members provide emotional support. Groups of knockerettes who live near to one another will arrange to meet up for 'knit and natters' as well as for fundraising events. The haberdashery section of large department stores such as John Lewis, Marks and Spencer or Debenhams often provide the venue for meet ups and are ideal opportunities to reach out to shoppers, raise awareness of the charity and its work and to fundraise.

The KKUK's open Facebook page provides comments from volunteers who tell what inspired them to join and make knockers. The incentives range from wanting to ensure that all women have a choice and are aware of what is available to them, having undergone a mastectomy and experienced the difficulties of a silicon prosthesis, to losing a close friend to breast cancer and wanting to help. The commitment of the volunteers is very clear in many of the comments:

I have made hundreds and hundreds of knockers [...] and only take 2 weeks off a year when we go abroad [...] The knowledge that I am helping so many women is my motivation and the realisation that it could so easily be me at any time that needs this support. I am constantly amazed at the numbers of women that we help and am very grateful that FB put me on this path. (<https://www.kkukciowix.com/why-volunteer>)

Thanks to the success of some of the fundraising campaigns for cancer research there is an odd association of breast cancer with pink, fluffy and feminine. From an autoethnographic perspective MacDonald can confirm that being diagnosed with and treated for breast cancer is none of those things. Once diagnosed you are swiftly transferred to a world of hospital waiting rooms and treatment areas, which might be thoughtfully decorated but are often impersonal and uninspiring. The equipment you see and use on a regular basis when receiving treatment is functional and frightening. Some of the chemotherapy used is so sensitive to light it is hung from the drip stand wrapped in black to insulate it. This hard, cold logical world is a long way from the romanticised world created by the fundraising marketing teams. This is a time when as a patient you are emotionally vulnerable, anxious and worried about what is happening to you in the present and concerned for what might happen to you in the next few weeks and months; and if you are lucky enough and the medication, surgery and radiotherapy are effective, what might happen to you in the future. As a recipient of a Knitted Knocker MacDonald can also confirm that it represents so much more than a practical substitute for a mass-manufactured product; it is a huge emotional boost in the middle of a long and often difficult process of treatment and has a profound effect on the recipient's wellbeing. Fellow recipients of Knitted Knockers demonstrate the depth of their emotional response by leaving comments on the KKUK website: 'The love and care you put into it [the Knitted Knocker] for a stranger made my heart melt' (<https://www.justgiving.com/knitted-knockers>).

Once ready, a parcel containing the prosthesis is either hand-delivered or sent through the post and is accompanied by a hand-written message in a card of their choice from the knitter to the recipient, along with a KKUK card which says 'Made with love and filled with hope', additional kapok stuffing, and a small packet of love-heart sweets. They are contained within a translucent bag, tied with a silk ribbon (Figure 1). Together the contents of the parcel communicate a deep sense of the knitter's personal care for the recipient.

[Insert Figure 1 here]

The way the parcel is presented clearly indicates that here is a treasured object intended for you, rather than it being another element in the medical process to be coped with and endured. Comments on KKUK Facebook page attest to the depth of the emotions evoked by the parcels:

Thank you so very much for the beautiful gift bag of knitted knockers I received last week from your knitting volunteer. I was in tears over how beautiful and soft they are, and how personalised the presentation was including a beautiful heartfelt card. It has been such a struggle over the years to connect with anyone who is as understanding and generous as your group of knitters.

(<https://www.facebook.com/knittedknockersuk/>)

That the Kocker is hand-knitted is particularly important in highlighting this sense of being presented with a unique object. Tactility is a particularly sensitive element given the intimacy of the object, since the recipient will wear the prosthetic next to their skin, and for some next to their heart, every day. So, the message of love, care and protection is a welcome reassurance. Turney comments that:

[...] the combination of touch and the knitted object particularly when it is a gift, establishes a tactile relationship between the maker and intended recipient. This tactility is both actual and metaphorical, implying a desire in the maker to literally touch, protect or nurture the recipient [...] (Turney, 2012, p.308)

Moreover, the prosthesis is provided as a gift, so it is immediately within the realm of the personal and private unlike a synthetic prosthesis which is bought on-line or accessed via the National Health Service. Anthropologist Marcel Mauss argues that the gift is much more than the giving of something (usually an object) from one person to another: for him it is representative of a 'fleeting moment when a society and its members take emotional stock of themselves and their situation as regards others' (Mauss, 1967, pp. 77–78). The passing of a gift from maker to recipient represents a network of socialisation, arising from the vulnerability of the recipient which in turn stimulates the need to demonstrate care and concern in the form of a gift. Gift-giving has a long association with times of transition or transformation such as significant birthdays, weddings and other rites of passage. The loss of a breast also represents a time of transition, with many women dividing their lives into pre- and post-breast cancer diagnosis timeframes. This is where the loss of one's femininity can be keenly felt and where as described above, surgeons often step in to provide reconstruction to help a woman reclaim her former self. There is no right or wrong answer to decisions about opting for or against reconstruction. Again, comments on KKUK Facebook page confirm their role in improving the wearer's confidence and sense of well-being:

My mum has asked me to email you to thank you for her knitted knockers. They are absolutely brilliant and fit perfect. Thank you for all you have done as mum's confidence has returned now she feels she looks good in her tops.

(<https://www.facebook.com/knittedknockersuk/>)

A hand-made gift in any context represents skill and time, a giving of oneself to convey a heartfelt or genuine sentiment:

It is 'special' or rare because it is handmade and perhaps customised; sophisticated because the making of the object required skill; it is precious due to materials or time invested in labour; it is expressive – in terms of subject-matter, function, traditional or historical reference; and it is enduring. (Hickey, 1997, p.85)

It is this combination of gift, skill and time which provides the Knitted Kocker with its strong emotional kudos for both the maker and the recipient.

Discussion and Conclusion

Digitally networked spaces, such as Knitted Knockers, provide important opportunities for creative collaboration, by positively engaging and impacting their participants and recipients. The psychological and social benefits of knitting are well-documented (Corkhill, Hemmings, Maddock and Riley, 2014). As a physical process, knitting is repetitive and absorbing, fully occupying hand and mind, and inducing a 'meditative' and 'mindful' mental state (Matthews, 2017 p.8). This form of creative activity, described by Csikszentmihalyi (1997) as 'flow', arguably promotes happiness and well-being. Combined with the positive feelings associated with producing a 'Kocker' for a breast cancer patient, this makes for a powerful sense of purpose and reward for the maker.

The social benefits of the Knitted Kocker project are equally important. Knitting may be thought of as a solitary activity but increasingly, through social media knitting groups, it provides an opportunity for social connection and the forming of communities (Corkhill, Hemmings, Maddock and Riley 2014; Kenning, 2015). The ability to contribute to one's community is recognised by the World Health Organisation as a key part of good mental health and well-being (WHO), and the Knitted Knockers initiative is a positive example of this.

[Insert Figure 2 here]

The Knitted Knockers project effectively creates two communities: by bringing together knitters in a virtual and physical environment, and forming a community of Knitted Knockers recipients. Although these two communities never physically meet, they form a strong metaphorical solidarity through the shared experiences of giving and receiving, each enhancing the well-being of the other. As Mary Douglas writes in her foreword to Mauss's *The Gift*: 'the theory of the gift is a theory of human solidarity' (Mauss, 2002, p.xiii). Knitting for charity has been discussed as providing a means for the knitter to create a new positive identity (Corkhill, Hemmings, Maddock and Riley, 2014, p.40). For women who decide against surgical reconstruction, the Knitted Knockers can also represent a positive step towards reclaiming her new identity. For the community of makers the Knitted Knockers indisputably represents caring in action with both the knitters and the recipients being connected through this materiality of care.

The dual authorship of this article provided an opportunity for two perspectives to be merged, one author offering an objective view of the societal 'norms' and post-surgery possibilities for women post-mastectomy, the other a more personal response to the impact of receiving and using a Knitted Knockers from a deeply committed group of makers. The qualitative data gathered and the autoethnographic insights present an invaluable opportunity to provide a rounded reflection on the value of participatory textile making projects. The evidence provided from our research led us to conclude that the Knitted Knockers are a positive and empowering move for all involved in their creation and use, and as such they function exactly as the label says (Figure 2), being an emblem of love, hope and resilience.

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¹ Sandell writes that 'Of women undergoing mastectomy ... only about 25 percent undergo reconstruction' (Sandell, 2008, p.339).

² See: Broom, D., 2001, Reading Breast Cancer: Reflections on a Dangerous Intersection. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 5(2), pp. 249-268; Datan, N., 1989, Illness and Imagery: Feminist Cognition, Socialization and Gender Identity, in M. Crawford and M. Gentry (eds.), *Gender and Thought: Psychological Perspectives*. New York: Springer Verlag; Lorde, A., 1980, *The Cancer Journals*. London: Sheba Feminist Publishers; Metzger, D., 1981, *Tree*. Culver City, CA: Peace Press; Sontag, S., 1979, *Illness as Metaphor*. London: Routledge.

³ These may include: postoperative pain, changes in skin sensation, bruising, haematoma, seroma formation, infection, fat necrosis, scarring and delayed wound healing. Further surgery may also be required to improve the appearance of the reconstructed breast (Rolph, Mehta, Farhadi, 2016, p. 334).